

Connecting Minds

Dementia Care Newsletter

.. Wisconsin Bureau of Aging and Long Term Care Resources ..

.. Division of Disability and Elder Services .. Department of Health and Family Services ..

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Featured Experts:

Pain – How Can You Tell?

Recognizing pain in people with Alzheimer's disease

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Although some people may develop painful conditions such as arthritis as they age, pain is not a part of “normal aging.” However, many people feel that pain is an inevitable part of the aging process that can't be treated. This belief is one of many barriers that can lead to under-treatment of pain in older adults. Another significant barrier can be dementia.

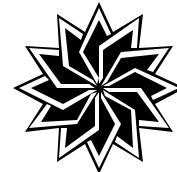
“Research is very clear that people with dementia are under-treated for pain.” – Dr. Christine Kovach, UW-Milwaukee researcher & author of a 5-step process to assess and treat pain in people with dementia: ‘Assessment of Discomfort in Dementia Protocol’ (or ‘ADD’). “We need to honor these people and look at them in a different way. What are their behaviors telling us? And what interventions will improve their comfort, quality of life and human dignity”. (See page 5 for Assessment of Discomfort in Dementia Protocol)

Barriers to Detecting Pain

Dementia, specifically of the Alzheimer's type, may cause problems in communicating or detecting pain for both the person with dementia and the primary caregiver. Alzheimer's disease and related types of dementia cause two significant problems impairing a person's ability to report pain. Short-term memory problems can cause the person to become confused about the type of pain present, and for how long it's been experienced.

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Tips for Care Planning:



Coping with Incontinence

Prevention & Management Tips for Alzheimer's Caregivers

People with Alzheimer's disease and their caregivers worry about future incontinence. Although declines in cognition eventually do result in incontinence, it doesn't have to be a problem until late in the disease when physical capacity diminishes bladder control.

By understanding potential influences on a person's continence, caregivers can monitor and address problems that may arise, and plan for changes in ability. Issues that effect incontinence can be **environmental, medical, physical, emotional, or related to cognitive decline.**

Over time, the progression of Alzheimer's disease (AD) creates scar tissue in the brain impairing a person's skills and memories. *Continued on page 4*

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Secondly, damage to the area of the brain controlling speech can occur - impairing the person's ability to communicate verbally. The combined effects of these problems may result in the person being unable to say she is in pain. Instead, she may communicate her pain by behaving in strange, different or more agitated ways.

"People need to recognize that 'behavior problems' are symptoms of unmet need in people with dementia. Historically, these issues have been looked at from a psychological perspective. When we also assess physically for pain, we find that the person is either in pain or has another unmet need – our job is to figure out what the unmet need is, and address it." – Dr. Kovach

In addition to the caregiver having difficulties understanding the person with dementia, caregivers may not believe the person is truly in pain because her actions don't seem pain related. Some caregivers could also incorrectly assume that a person with dementia isn't able to feel pain due to the impairments of the illness.

Addressing the Barriers

To remove barriers for the person with dementia receiving adequate pain treatment to experience a better quality of life, there are multiple strategies. Training caregivers and providing them with methods of pain assessment to use systematically and consistently is important in addressing the pain of the person with dementia.

Pain Assessment Tool for Family Caregivers:

"Assessing Pain In Loved Ones With Dementia" To access pain scales and other information to help older adults experiencing pain, go to **American Geriatrics Society** web site:

http://www.americangeriatrics.org/education/manage_pers_pain.shtml

Or call: 1-800-247-4779

Detective Skills

Training caregivers (of all types) to understand that pain is real for a person with dementia, and to collect clues from the person, is essential. Simply put, to identify pain in persons unable to verbally communicate requires a caregiver to be an investigator or detective. What clues might caregivers collect? They need to think about how they might act if they were in pain. Grimacing, frowning, screaming, fidgeting, or avoiding doing

things that cause the pain may be a sign or a clue that the person may be in pain. (See below)

Common Behavioral Symptoms Associated with Pain in People with Dementia* (*Source: ADD Protocol – Dr. Chris Kovach)	
Facial Expression	Grimace, frown, tightly closed/wide open eyes. Frightened, weepy, worried or sad looks
Mood	Irritable, confused, withdrawn, agitated, aggressive
Body Language	Tense, wringing hands, clenched fists, restless, rubbing/holding body part, hyperactive, inactive, noisy breathing, guarding body part or guarded movement
Voice	Moaning, mumbling, chanting, grunting, whining, calling out, screaming, crying, verbally aggressive
Behavior Changes	Change in appetite, sleep, mobility, gait, physical function, participation, exiting or wandering, elopement, physical aggression, socially inappropriate or disruptive, resists care
Other Possible Changes or Clues	Incontinence onset, falling, hypersensitive to previously tolerated things, self-neglect, pacing, sleep problems, physical symptoms of illness like fever, etc.

Pain Assessment: Getting the Right Information

Traditional pain assessments in formal healthcare settings rely on a variety of pain assessment tools, like pain intensity scales, to measure presence and intensity of pain. In addition to these scales, a good health history of the person is critical.

Historical information on the person's health and life may provide clues to pain probability. For example, knowing the person had cancer or an injury in the past may suggest that the condition and related pain may be re-occurring. Previous injuries, chronic conditions (like arthritis, dental problems) and acute problems (skin breakdown) are also pain risks. It is especially important to gain health history information

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from other reliable sources other than just the person with dementia, because this information will provide valuable clues for physical assessment and interventions.

Using Pain Intensity Scales

Pain intensity scales have been developed to help caregivers question the person in pain. These scales can be extremely effective, even with persons who have dementia. By regular questioning, caregivers can identify if the pain is getting better or worse, and if treatments are working. Examples include the “1-10 scale” and the “verbal analog scale” that identify pain intensity at mild, moderate or severe levels, and the “faces” scale which has cartoon like facial expressions depicting levels of discomfort from smiles to tears. Even if a person with dementia can’t verbally communicate, she may understand one of the scales and use nonverbal ways to indicate pain. Studies have shown that caregivers must try multiple scales for people with dementia, to find out which one is the most effective.

Caregivers that know the person with dementia may sense the person’s pain through a combination of intuition and feelings resulting from observations.

Pain Scales: go to Partners Against Pain:

http://www.partnersagainstpain.com/html/assess/as_scale.htm

If a person who has dementia has a change in behavior, caregivers need to first address basic needs – hunger, the need to go to the bathroom, being too hot or cold, and/or repositioning. Changing the pace of the activities around the person to combat boredom or over stimulation should also be tried. If the person is still agitated, trying some Tylenol® may be an appropriate next step, if the physician approves. If behavior shifts, the pain reliever may be the answer. Once caregivers identify that the person with dementia is in pain, it is important to monitor the treatments provided. Questioning with the pain scales and observing behavior can monitor whether the pain is being controlled.

“Pain assessment must be done as a systematic and consistent process, repeated regularly.” – Dr. Kovach

Summary of the Assessment of Discomfort in Dementia (ADD) Protocol:

ADD is a 5-step process designed for nurses working in nursing homes, and is done to judge the underlying causes of a person’s discomfort when s/he is unable to communicate it. Physical pain and emotional causes of discomfort are both examined.

Summary:

- (1) Provide a complete physical assessment
- (2) Review the person’s health history for possible pain causing conditions, past injuries, etc.
- (3) Adjust the environment to provide comfort.
If the person’s discomfort is still not relieved:
- (4) Give a dose of approved pain reliever*
i.e., acetaminophen (also called Tylenol®)
because it is the safest for older adults
- (5) Monitor and routinely re-assess for pain

If these approaches fail, a physician is consulted for further intervention, possibly including administering stronger pain relievers or other type of medications depending on the person’s history and problems.

*Recommendations include NOT using anti-inflammatories such as Ibuprofen (Motrin, Alieve etc.) or aspirin because of drug interactions and/or side effects common to older adults.

To View ADD Protocol:

http://www.uwm.edu/Dept/ageandcommunity/who/leadership_ckovach.html

Pain must be consistently brought under control. Providing routine pain medication around the clock – or avoiding “as needed” medicating – assures the person with dementia has appropriate pain relief. One should not rely on the person telling you they need more medication. This is especially troubling to people with dementia, because they may not be able to ask for the medication. “As needed” medication can be prescribed for break through pain – the times when symptoms occur because the pain is more than usual. ❖

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Doug’s Newsletter Web Site:

http://www.dhfs.state.wi.us/rl_DSL/Publications/PharmCapsule.htm

UWM Center for Age and Community: 414-229-2740
agecom@uwm.edu

ADD Article in Age & Community Newsletter:

http://www.uwm.edu/Dept/ageandcommunity/resources/docs/AgeWise_V1_I3.pdf

Common Issues Influencing Incontinence

Medical Issues

Possible Problems	Possible Strategies
<ul style="list-style-type: none"> ♦ <u>Medications</u>, caffeine, alcohol For bowel incontinence only: <ul style="list-style-type: none"> ♦ <u>Food sensitivities</u>, allergies ♦ <u>Irritable bowel syndrome</u> or colitis ♦ <u>Celiac disease</u> or sprue: an allergy to gluten products (common in people with Down Syndrome) 	<ul style="list-style-type: none"> ♦ Consult doctor for medication alternatives ♦ Eliminate or water down alcohol ♦ Disease screening & treatment ♦ Reduce/eliminate caffeine, allergic substances ♦ Gluten free diet
<ul style="list-style-type: none"> ♦ <u>Illness/infection</u>, urinary tract or bladder infection ♦ <u>Diabetes</u> ♦ <u>Constipation</u> ♦ <u>Lack of adequate fluid intake</u> to stimulate bladder sensations 	<ul style="list-style-type: none"> ♦ Watch for agitation as an indicator, get a thorough medical exam and treatment ♦ Increase fiber intake ♦ Encourage many varieties of fluids, high intake during day and low in evening
<ul style="list-style-type: none"> ♦ <u>Prostate problems</u> (men) ♦ <u>Childbirth</u> (women) ♦ <u>Obesity</u> ♦ <u>Physical inactivity</u> and resulting muscle weakness ♦ <u>Bladder spasms</u> 	<ul style="list-style-type: none"> ♦ Routine regular exams for men ♦ Screening for women ♦ Surgical correction or adaptive aids ♦ Weight loss, increase activity level ♦ Strength training of muscles, walking ♦ Medication to decrease spasms
<ul style="list-style-type: none"> ♦ <u>Chronic pain</u>, stiffness, arthritis etc. ♦ <u>Undiagnosed fractures</u> (especially tailbone, spine) very common in frail people 	<ul style="list-style-type: none"> ♦ Medical screening for past injuries and current conditions that could cause chronic pain (see related article <i>page 2</i>) ♦ Treat conditions/ pain medically, adapt toileting conditions-more comfortable (padding, using a commode that can be repositioned, etc.)
<ul style="list-style-type: none"> ♦ <u>Skin breakdown</u> conditions resulting from incontinence 	<ul style="list-style-type: none"> ♦ Encourage person to change and clean with wipes often ♦ Change position while sitting/lying down frequently, alternate sitting/standing often ♦ Treat with protective lotions/creams, cornstarch, etc.

Physical Limitations

Possible Problems	Possible Strategies
<ul style="list-style-type: none"> ♦ <u>Mobility problems</u> 	<ul style="list-style-type: none"> ♦ Assess person and home by having a medical therapeutic evaluation (OT/PT) ♦ Utilize adaptive equipment which allows better mobility, wear good shoes/slippers
<ul style="list-style-type: none"> ♦ <u>Visual Changes</u> – depth perception decreases, dark/black colors look like holes (visual cliffs), patterns are confusing and look 3D ♦ <u>Items that are out of sight are out of mind</u> (not perceived) 	<ul style="list-style-type: none"> ♦ Provide contrasting colors floor/walls/toilet so person can see toilet clearly ♦ Cover busy patterned floor tile (uniform color) ♦ Install grab bars that are in person's frontal vision field that can be seen during use
<ul style="list-style-type: none"> ♦ <u>Decreased/slowed hand coordination</u> 	<ul style="list-style-type: none"> ♦ Use clothing with easy-open, wrap around or pull down features person can undo quickly ♦ Use minimal protective pads to catch leakage

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Overall Alzheimer's Disease Progression

First, the part of the brain (called the hippocampus) that translates present experience into long-term memory is damaged. This results in a person having difficulty learning new skills and remembering new information as the disease progresses.

Secondly, a person loses the more complex recent skills and memories of adulthood first, and then reverts backwards in skill level and orientation to time. This is commonly referred to as "first in last out" (meaning things learned first are the last to go.) As a result, a person in mid to later stages of the illness may believe himself to be a younger person and think that the scenarios of that time in his life are current.

Early Stage

Early in the disease, the basic toileting skills that have been used over a lifetime remain fairly intact. Medical, emotional or unpleasant environmental issues usually cause incontinence problems at this time. For example, pride can prevent the person from admitting a problem, making it harder for medical

Common Issues Influencing Incontinence

Environmental Issues

Possible Problems	Possible Strategies
<u>Access:</u> <ul style="list-style-type: none"> ♦ Cluttered path ♦ Distractions (pictures/mirrors/mail, etc.) ♦ Mobility & navigation problems ♦ Can't recognize or remember which room is bathroom ♦ Can't remember how to find toilet upon awakening 	<ul style="list-style-type: none"> ♦ Clear path to bathroom, and bathroom itself, of clutter and distracting items ♦ Mark pathway on floor with colored electrical tape to provide a guide path ♦ Add grab bars to hallway walls for person's stability ♦ Use signs to identify room: picture of toilet and word person uses for it, arrow pointing towards the door ♦ Install motion-sensitive lights in bedroom, hallway, bathroom; can also connect motion sensors to voice prompts that give recorded directions ♦ Position bed and bathroom door so toilet is visible from bed, is lit with night light to provide visual cues
<u>Ease of use:</u> <ul style="list-style-type: none"> ♦ Physical comfort, safety, ability to get up and down ♦ For men: the ability to stand, aim, hit the target 	<ul style="list-style-type: none"> ♦ Install grab bars on either side of toilet and on wall for person to stabilize self when standing ♦ Install a raised toilet ♦ Use cushioned toilet seat, raised footrest ♦ Make floor, walls and toilet contrasting colors – put "target" in toilet (men), remove wastebaskets
<u>Privacy</u>	<ul style="list-style-type: none"> ♦ Provide cover for the person: a door, curtain, blanket, robe, or special adaptive clothing ♦ Respect privacy: step out but be near for their call ♦ Clean person while covered, or from behind if person prefers it
<u>Appeal of the room:</u> <ul style="list-style-type: none"> ♦ Cold temperature sensitivity ♦ Noise ♦ Unpleasant smells of urine/feces, ♦ Lighting (too little/too much, ability to turn switch on & off) ♦ Does it look familiar? (like home from past) 	<ul style="list-style-type: none"> ♦ Make room more inviting: warm, pleasant smells (plug in deodorizer, potpourri, flowers, etc.) offer magazines to read ♦ Store soiled garments in sealed container away from bathroom ♦ Minimize odors: use only cotton clothing, put 2 TBS of mouthwash in catheter bag to deodorize ♦ Determine if person used outhouse, chamber pots etc.: consider adapting door to bathroom to look like an outhouse, using commode in bedroom, etc.

Cognitive Decline Issues

Possible Problems	Possible Strategies
<ul style="list-style-type: none"> ♦ <u>Unable to "learn" a new product</u> (e.g., how to put on a "depends") ♦ <u>Frame of reference may be different than the present</u> (e.g., may think still using an outhouse) ♦ <u>Ability to verbally communicate may be impaired</u> 	<ul style="list-style-type: none"> ♦ Use absorbent products similar to familiar undergarments, provide access to in familiar place ♦ Incorporate changes that need to be made by introducing them into familiar routines (e.g., new types of clothing that may be easier to get on/off, etc.) ♦ Do toileting, changing clothes and undergarments etc. in the bathroom (or room person associated these activities with in the past) to build from previous associations and maintain skills ♦ Watch for body language: pacing, holding self, etc. which may indicate a need to use the bathroom ♦ Provide pictures for person to point to as aids for person to communicate what is needed

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issues to be identified and addressed. Unpleasant smells, temperatures, privacy issues or unfamiliar surroundings may also play a role.

Middle Stage

In the middle stages of AD, cognitive decline begins to play an important role. Here the caregiver can adapt the environment to help the person find, get to, want to use and easily use the toilet. In addition, limiting diuretic - or bladder/bowel stimulating – drinks or foods, and balancing fluid intake will assist the person with AD. Monitoring for medical issues that at any stage can cause sudden cognitive decline, but in mid stage the person may not be able to report medical problems, so caregivers must watch for them. The person with AD also becomes much more sensitive to stress and emotional influences in middle stages, and may have catastrophic reactions to being assisted.

Late Stage

Eventually, in late stage AD, the brain gets the signal that the bladder needs to be emptied, but the brain can't remember what the signal means. This causes loss of control over continence.

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Common Issues Influencing Incontinence

Emotional Issues

Possible Problems	Possible Strategies
<ul style="list-style-type: none"> ◆ <u>Pride</u> (e.g., hides problem, refuses help, hides soiled garments, etc.) 	<ul style="list-style-type: none"> ◆ Provide understanding, dignity and assurance that problem is common and the person can be helped ◆ Discuss with MD prior to appointment for discreet inquiry for testing at appointment ◆ Use neutral 3rd party (perhaps professional of same gender or trusted person) to discuss the problem with the person
<ul style="list-style-type: none"> ◆ <u>Past habits & associations</u> (e.g. read on toilet, avoids public restrooms) ◆ <u>Pattern/routine</u> (times of day, place) 	<ul style="list-style-type: none"> ◆ Find out previous habits, schedules and routines and duplicate as much as possible to provide sense of security ◆ Offer routine trips to the bathroom, (also during night), change person's clothes or undergarments while sitting on commode
<ul style="list-style-type: none"> ◆ <u>Abuse</u> – current or previous (Note: A person may have symptoms like being sensitive/defiant to being touched in private areas, or display fears of being physically harmed by wincing/cringing, or fear of being verbally ridiculed that may offer care providers clues that abuse may have occurred) 	<ul style="list-style-type: none"> ◆ Use gentle/reassuring approach, gender sensitivity, give person choices, allow to assist to give feeling of control in situation ◆ Ask permission to touch. Touch only when person can see and acknowledge you to avoid startling, allow plenty of time ◆ Talk through the care you will be and are giving out loud to inform and reassure ◆ assign one trusted person to do care, not multiple caregivers, or people who are interpreted to be strangers that upset ◆ Identify and avoid/minimize triggers that cause emotional reactions ◆ Use pleasant distractions during toileting and care: music, singing, talk, jokes, etc.

There are a variety of protective undergarments, bed liners, chair covers, skin products, easy to open or remove clothes and strategies that help caregivers keep the person in late stage as clean and dry as possible while preventing skin breakdown and odors.

Family Caregivers

Another important consideration involves the role family caregivers have. When caring for continence problems, a shift can occur in the caregiver's relationship with the person with AD, yielding subtle yet powerful results. When a spouse or child begins to provide functions that create a role reversal (they take on "parent" type tasks for the person with AD), the caregiver may experience a variety of stressful emotional issues. It is important for caregivers to recognize that they have choices and can receive targeted assistance for these emotional situations, which help keep the relationship intact.

In summary, a caregiver must consider ways to help the person with dementia find the toilet, get to it, see it and use it. See accompanying charts for ideas on some common issues and maintenance strategies related to incontinence in people with Alzheimer's disease. ❖

What's On the Web? Tips for Incontinence Care:

Caregiver.com Magazine

www.caregiver.com/articles/alzheimer's_incont.html

ADEAR <http://www.alzheimers.org/unraveling/index.htm>

A Healthy Me.com

[http://www.ahealthyme.com/topic/alzincont;\\$sessionid\\$510C0WYAAA1XOCTYAIRTEMQ](http://www.ahealthyme.com/topic/alzincont;$sessionid$510C0WYAAA1XOCTYAIRTEMQ)

Alzwell Caregiver Help – Eldercare Skillbuilders

<http://www.ec-online.net/Knowledge/SB/SkillBuilders.htm>

Kitchen, Bathroom or Other Signs:

Signmaker OnLine 888-523-2069

Northwest Builders Network 888-810-8296

Healthcare Signs 316- 263-9441

Ideas? Suggestions?

Contact us!

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Missed a previous issue? Go to:
<http://www.dhfs.state.wi.us/aging/dementia>